PPI Strategy 2027 – beyond, Survey Responses

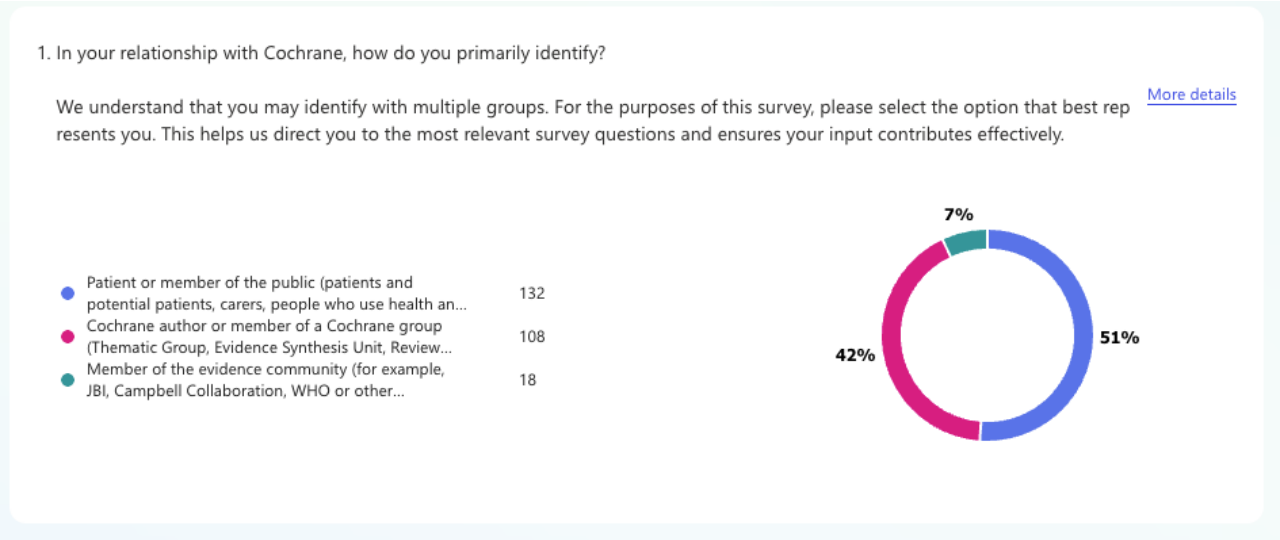
Survey opened: 11 November 2025

Survey closed: 19 December 2025

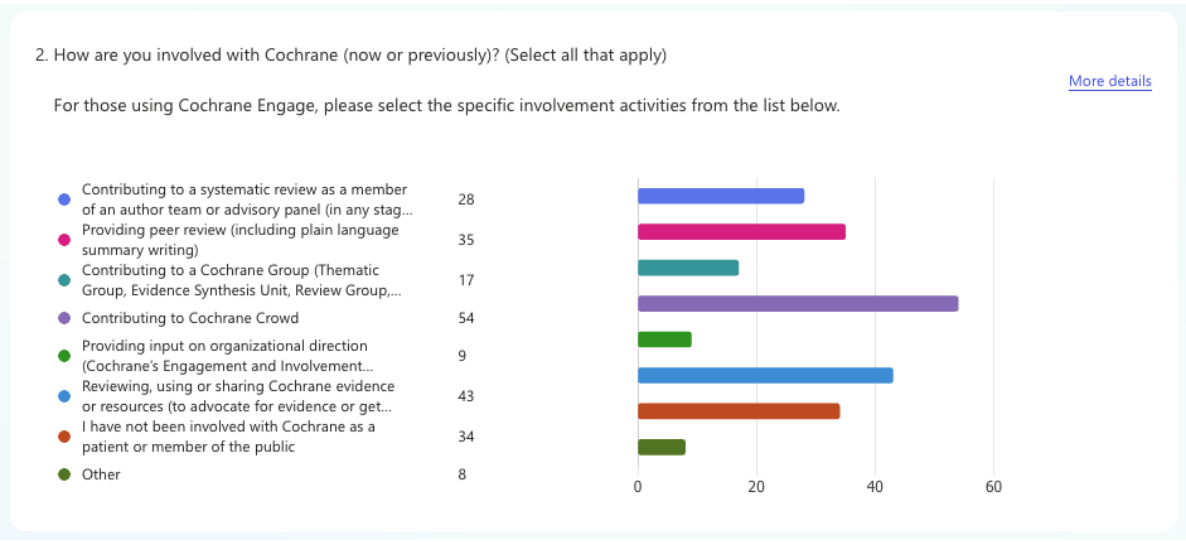
Total responses: 258

Survey analysis: February 2026

Note: The themes and representative quotes below focus specifically on suggestions for improving or innovating Cochrane's work. Quotes that solely expressed pride or congratulations, or that were irrelevant to the survey or to PPI, have not been included. Any potentially identifying information has been removed to protect anonymity.

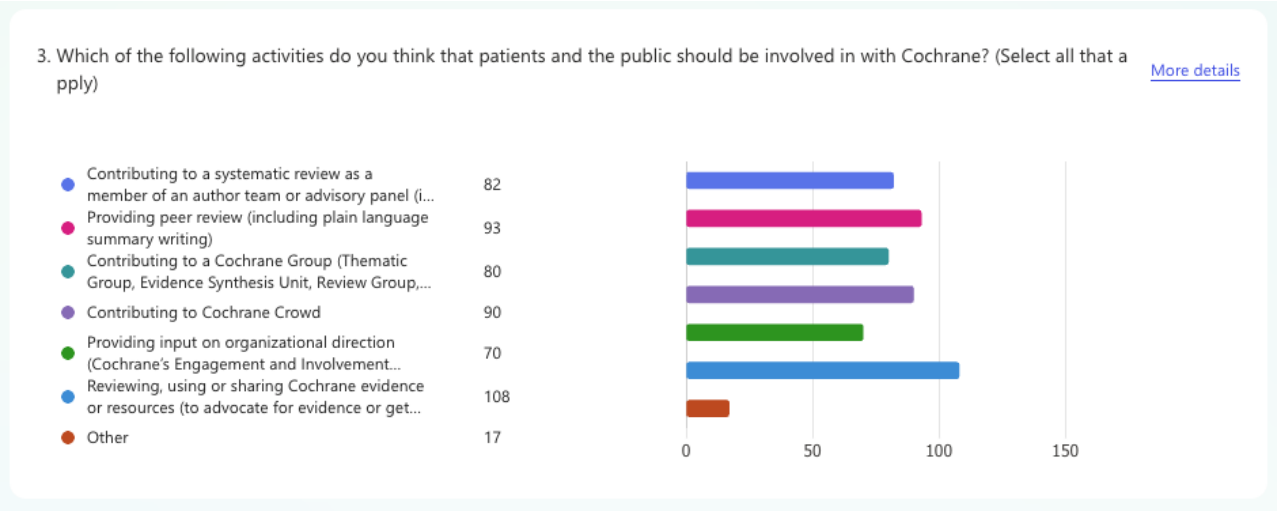

1. In your relationship with Cochrane, how do you primarily identify?
We understand that you may identify with multiple groups. For the purposes of this survey, please select the option that best rep resents you. This helps us direct you to the most relevant survey questions and ensures your input contributes effectively.
More details
Patient or member of the public (patients and potential patients, carers, people who use health an... 132
Cochrane author or member of a Cochrane group (Thematic Group, Evidence Synthesis Unit, Review... 108
Member of the evidence community (for example, JBI, Campbell Collaboration, WHO or other... 18
7%
42%
51%

Patient / public responses:


2. How are you involved with Cochrane (now or previously)? (Select all that apply)
For those using Cochrane Engage, please select the specific involvement activities from the list below.
More details
Contributing to a systematic review as a member of an author team or advisory panel (in any stag... 28
Providing peer review (including plain language summary writing) 35
Contributing to a Cochrane Group (Thematic Group, Evidence Synthesis Unit, Review Group,... 17
Contributing to Cochrane Crowd 54
Providing input on organizational direction (Cochrane's Engagement and Involvement... 9
Reviewing, using or sharing Cochrane evidence or resources (to advocate for evidence or get... 43
I have not been involved with Cochrane as a patient or member of the public 34
Other 8
0
20
40
60

Other:

- Wikipedia
- Attended colloquium


3. Which of the following activities do you think that patients and the public should be involved in with Cochrane? (Select all that apply)
More details
Contributing to a systematic review as a member of an author team or advisory panel (i...
82
Providing peer review (including plain language summary writing)
93
Contributing to a Cochrane Group (Thematic Group, Evidence Synthesis Unit, Review Group,...
80
Contributing to Cochrane Crowd
90
Providing input on organizational direction (Cochrane's Engagement and Involvement...
70
Reviewing, using or sharing Cochrane evidence or resources (to advocate for evidence or get...
108
Other
17
0
50
100
150

Other:

Theme	Sample quotes from theme
Leadership	Being involved in the Cochrane in the executive team as well as the governing board Patients and public should be involved in should be involved in all aspects and activities including evolving Cochrane for the next generation Contributing to the inner workings of the organisation to ensure compassionate integration of patient perspectives Patients and the public should be involved in every aspect of Cochrane. For example, in addition to the above, they should sit on all key management groups of Cochrane - including marketing/communications/outreach
Training / guidance	Providing feedback on training Personally think there is an urgent need to educate public as to what is evidence versus opinion or populism or sound bites. Also Ask public and patients what evidence reviews they value

What barriers currently prevent you from being more involved with evidence synthesis and/or Cochrane?

Theme	Sample quotes from theme
Time (By far mentioned the most)	Recent medical diagnosis thats taking up time. I used to volunteer online much more. I can't afford to volunteer so much of my time anymore. It's in my spare time, not in my work time and I need time to look after my health.
Awareness	Unaware I could participate or contribute to Cochrane work. ... some patients/public are both interested and capable of learning to contribute to all stages and tasks, rather than simply being restricted to plain

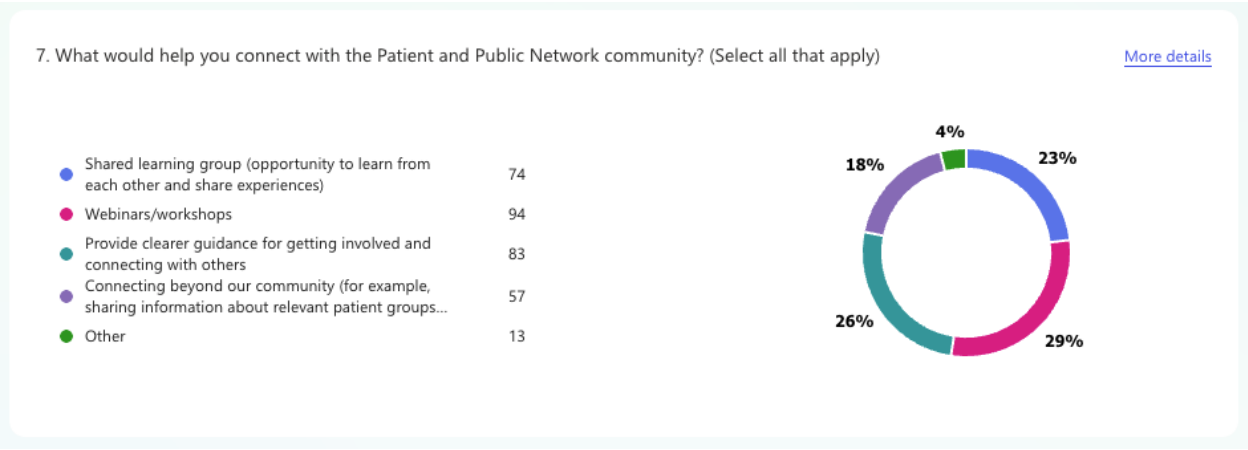
	language summaries. In Cochrane, it seems difficult to get involved in Cochrane groups beyond signing up to mailing lists or occasional surveys, group activities and meetings seem closed to new members unless you already know someone on the inside to contact directly which is unlikely.. I've never been invited to be involved in any other way. I have no idea how to get involved with Groups - their websites don't make it clear how to reach out. Difficult to find opportunities, opportunities are limited e.g. most are for plain language summaries or review, but rarely other activities. Difficult to get involved in groups as they are full or unwilling to consider new members. ...Requests for PLS reviews request someone with direct experience of the condition or treatment. I am capable of making valuable editing contributions regardless of my personal experience, but I am not certain how welcome my input is when I don't have the personal/lived experience with the topic. Lack of involvement in Cochrane's activities, other than Cochrane Crowd... I would very much like to be involved in authoring a systematic review, but I am not, at present, a member of a review group.
Disconnected	I never hear much from Cochrane. When I joined I thought I would get emails asking me to review but I've had nothing (I don't know what is Cochrane Crowd) ...not really having a sense of 'belonging' Slow or no response from task applied for on Cochrane engage. Diffcult to approach. Not easy to contact concerned ...isolation from group members
Confidence	Lack of confidence in my ability to contribute Not having the medical knowledge, just the Consumer/Lived Experience I don't understand it a lot of the time it is quite technical Do not have a medical background or education. I'm just interested in health issues Systematic reviews can be intimidating at first unless you do research and this "initial" impression will cause many individuals to not see them as relevant to patients and the public.
Compensation / financial	I am not paid for most of the engagement work I do with Cochrane. Most patient/public representatives want [need] payment for their involvement. Academics and clinicians are often on very high salaries and can afford to give-up their time for Cochrane for free - many patient/public/carer representatives simply cannot afford to do that. ...I cannot afford to manage a job and my conditions, and volunteer without remueration. HCP can integrate engagement into their work and further their career with this work. Patients can't. Finances is a barrier, I am from low income country and our Internet services are expensive and not fully functional
Language	My English isn't good enough.

	The language used - terminology is really important and can be off-putting when language is used routinely that may not be accessible or readily used by others outside the area of specialism. I don't understand it a lot of the time it is quite technical
Complexity	No easy or simple way for busy professionals or people living with illnesses to understand what Cochrane does and ways to get involved ...Barriers I experience do not prevent my involvement but they do make it harder. Like Editorial Manager being a very user-unfriendly system. Like Cochrane Engage saying I will be sent details of opportunities that reflect my interests but which never are. Like the multiple different Cochrane websites and having to sign in to different places (some of which cannot even be navigated to from some pages). It is all too fragmented and inconsistent. ...overwhelmed by explanation Having to log on to see work rathen than having it sent for invitataion... ...Generally for medical question I don't use the cochrane library, can't find my way there. I currently use consensus.app if I want to figure out things., like for instance about my diabetes, or supplements that may or may not be helpful. ...
Training / guidance	... training to understand evidence synthesis. ...assumptions are often made that everyone understands the practicalities or purpose of a process or processes involved in a specific task, when this is more often not the case especially when engaging with members of the public.
Expectations	understanding of expectations transparency, human judgment, and accountability I believe much of the work could be done using AI.
Practical support	More assistance to participate in different projects.

6. What kind of support would help improve your confidence about becoming involved in evidence synthesis and/or increasing your involvement with Cochrane? (Select all that apply)
More details
Mentorship opportunities 63
Connecting with peers/members of the Patient and Public Network 75
More learning and development resources 80
Practical support, such as assistance with technology (guidance with navigating virtual... 55
Better understanding the impact patients and public have on health research 58
Other 19
0
20
40
60
80

Other:

Theme	Sample quotes from theme
Opportunities	More opportunities to get involved in meetings and activities, to use the learning and expand on it, also opportunities to initiate patient-led reviews even on a small-scale to build confidence. More volunteering opportunities published that require review
Improved systems	Better, more user-friendly, integrated systems. ... I am very confident, I just need someone to get in touch and offer me a task. Make your website clearer about how members of the public can get involved, beyond Crowd and Engage. Reach out members about opportunities aligned with their interests. I need help understanding the process for submitting and evaluating proposals for studies generated by patients or the public. I need a point of contact or clear guidance to know if my project is appropriate and when to expect a response. Feedback loop and responsiveness and equal opportunity...
Practical support	Practical support, such as assistance with technology (guidance with navigating virtual platforms or connectivity issues) or travel (when applicable);Respecting that I'm a professional donating my time to the industry, making it QUICK and EASY to connect rather than log in here, do this, do that, tick this, check that...by that time I could have adone a review for you.; Give me tips on how I can get picked to work on a task. ; ... Human resource assistance to facilitate our in-person trainings for PPI mentees.;
Compensation / financial	Funding. I work to em d patient partnership in the health system but have no access to funds for research or training in evidence dissemination. Busy health professionals need quick information in easily digestible formats. Patient engagement and ppi could help with that. Financial support in health care Research ;
Other	Resources to support advocacy


7. What would help you connect with the Patient and Public Network community? (Select all that apply)
More details
Shared learning group (opportunity to learn from each other and share experiences) 74
Webinars/workshops 94
Provide clearer guidance for getting involved and connecting with others 83
Connecting beyond our community (for example, sharing information about relevant patient groups... 57
Other 13
4%
23%
18%
26%
29%

Other:

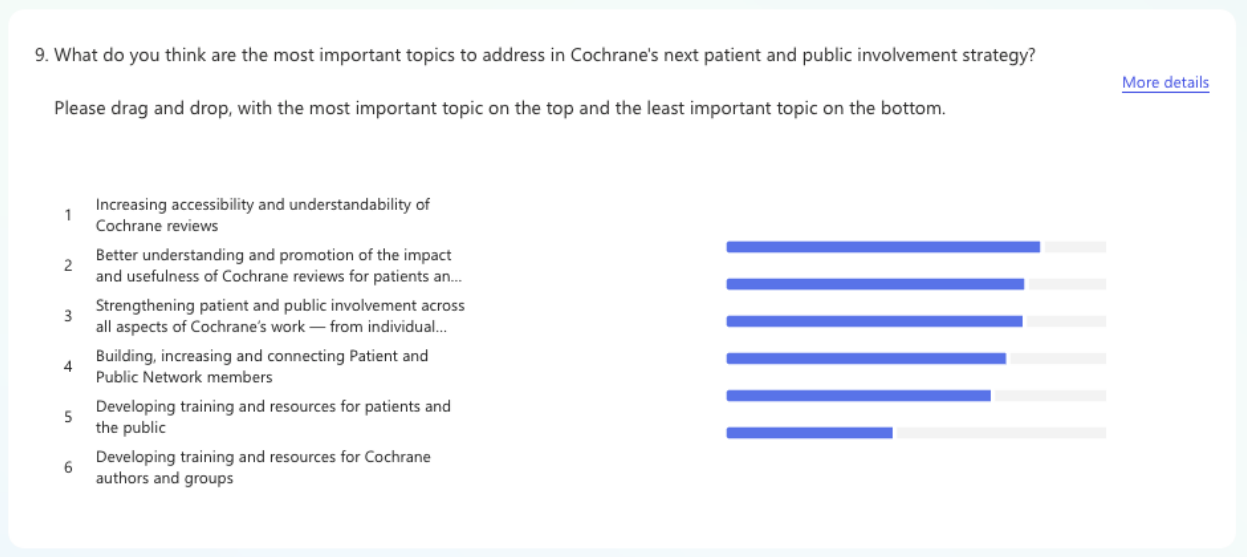
Theme	Sample quotes from theme
Not interested in connecting	But I'm not sure I want/need to connect to others. I simply wish to use my strong analysis, reviewing and editing skills to improve Cochrane studies.; Clearly invite me to relevant opportunities. I have no interest in connecting with random members of the public, but am interested in doing more to advance evidence-based medicine. ;
Awareness	I don't know what is the benefit of being in touch with the P&P network or even what it is.; Opportunities to join active projects or tasks as a learner;
Compensation / financial	PAYMENT!
Training / guidance	Regular meetings, community forums, working groups, learning circles, peer support networks, frequent small scale projects to build confidence and connections, perhaps a regular ECHO series etc.;
Other	Effective coordination of PPI activities amongst geographical field groups by way of PPI Coordinators who facilitate the implementation of Cochrane PPI strategy ; Media and Social Media campaigns that focus on how to obtain plain language review findings;

What would help you in making Cochrane reviews more accessible and understandable to patients and the public?

Specificity	search engine optimization for patient focused search, collaborate with patient groups to disseminate opportunity to serve and resources, link health care team, learners and patients to reference Cochrane works when planning care Disease specific resources and news More public facing communication, e.g. patient and public ambassadors presenting to community and patient groups and organizations, raising awareness, and better defined learning and activity paths for those new to Cochrane to learn about reviews, especially through peers A page where the topics offered can be selected by patient users, perhaps by linking to diseases, treatments, or therapies.
Training / guidance	Providing 'examples' of how to contribute (Cochrane is really good at doing this - the self-led/'optional' training I've already done has been really excellent). A guide on how to get started in writing a good accessible review
Collaboration	Co-production of reviews with patients/public partners Having more patients/public members involved in explaining, exploring and promoting.

	Making them widely available, such as advertising on patient and public led and run newsletters ...Perhaps it would help to try to place articles about Cochrane in influential health blogs and/or reach out to condition-based patient organizations that concern conditions which Cochrane has covered well. ...Following diagnosis there is too much info on the web. A Cochrane poster in doctors' office may assist ws as a valid source of unbiased information. Following diagnosis people need factual information and can be overwhelmed with resources on the web.
Language	More languages and mediated knowledge. More simple language, Summarized article for the public with local simple language without using complicated terms Native language and ease of searching
Communication	Cochrane Reviews would be more accessible to patients and the public if they used clear, jargon-free language with plain-language summaries that highlight the main take-home message first, offered layered levels of detail so readers can choose how much information they want, and used simple visuals to explain benefits, harms, and uncertainty. Making the evidence more relevant to everyday decisions, clearly stating who it applies to, and presenting benefits and risks side by side would improve understanding, while better accessibility through translations, easy-read formats, audio or video summaries, and mobile-friendly design would broaden reach. Involving patients in writing and testing summaries and sharing content through patient organisations and community channels would further ensure the information is meaningful and usable. I doubt the public go out looking for Cochrane reviews TBH. What would make them accessible is if common terms like "protein", "pathway" etc were avoided unless they were explained. In a medical context, both these examples have particular meanings. For most people, protein is sometyhingthat comes with chips or gravy and a pathway is what appears on the way to the shops the use of graphics and short cartoon videos more rather than text dissemination in different formats; audio, video etc. People are seeking knowledge with an evidence base for themselves and their communities however evidence based communities are competing against better Comms styles on hand held devices. You can't ultimately compete with that entirely but you can make the accessibility more appealing Working with time poor professionals and with marginalised groups, I think visual infographics, vlogs, recorded presentations in Ted talk style Video and infographic explainers; plain language summaries; "ambassadors" in the community Changing medical terminology to everyday language Basic explanation of the statistical tests used in the reviews and help in interpreting the results obtained with them and the criteria for their interpretation (e.g., effect size, significance level, etc.)

	Higher profile links, e.g. from health related news stories BBC and other news media
Access	Clearer understanding on accessing Cochrane Library and relevant papers. Free access to the Cochrane library. PLS make them understandable but accessibility and awareness is more of an issue. I'm not sure how to improve this! Easier access; Better communication around what is available or has been updated I think it's important to find out which groups of patients and member of the public you aren't reaching and explore outreach from there.
Other	From my personal experience, it's hard for the public to use Cochrane library in terms of design of websites in Cochrane.

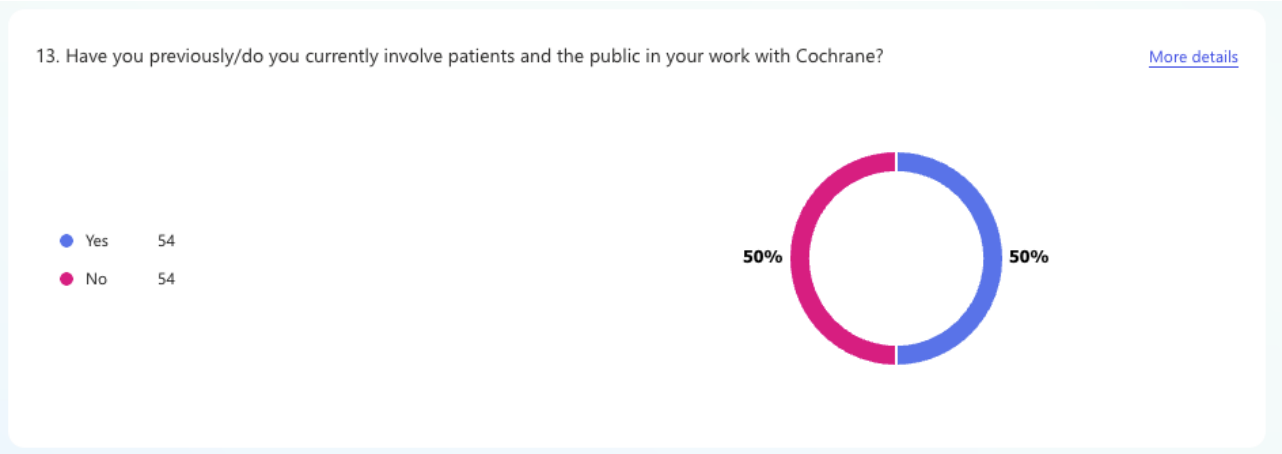

9. What do you think are the most important topics to address in Cochrane's next patient and public involvement strategy?
More details
Please drag and drop, with the most important topic on the top and the least important topic on the bottom.
1 Increasing accessibility and understandability of Cochrane reviews
2 Better understanding and promotion of the impact and usefulness of Cochrane reviews for patients an...
3 Strengthening patient and public involvement across all aspects of Cochrane's work — from individual...
4 Building, increasing and connecting Patient and Public Network members
5 Developing training and resources for patients and the public
6 Developing training and resources for Cochrane authors and groups

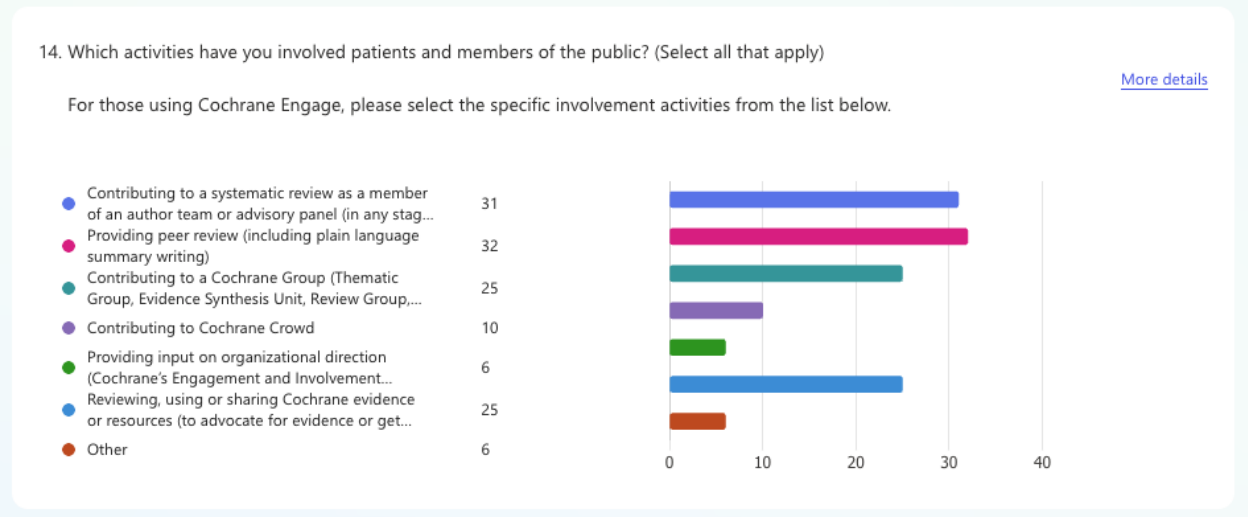
Do you have any further comments you would like to share based on your responses?

Theme	Sample quotes from theme
Disconnected	I've been trying to become more involved in Cochrane for nearly two years, but opportunities are sporadic and haphazard, with no clear path and no sense of community, it feels immensely challenging. Patients should feel that they are treated as a part of a review group, and not as guests. I feel underutilized by Cochrane. I enjoy contributing to Crowd, but the only other opportunity I've been offered is when something is posted to Engage about a condition I have experience with. I'd like to do more, but it's unclear how. Is there nothing else you could do with a supporter like me? Comparing it to other charities and organisations I work with I find the interaction I have is less friendly and informal I've joined the joined the Patient & Public Involvement Network twice, but still don't feel like I'm part of any kind of network - there are no opportunities to meet or hear from others in the network, no regular updates, no news about

	anything that's happening or how to get involved. How do I actually know I'm part of the network and how do I get actively involved? Sometimes it is unclear what a person should do? For example, I reported a task and it was not an actual task. It is still in my applications page and I don't know what should I do with it? Tap to end task? I haven't had anything to do. Or after assigning a task, an email informed me it has been deleted, however, it is still in my page.
Compensation / financial	Not providing adequate, funding for patient/public also sends a clear message about how much Cochrane does actually value PPI [= it doesn't!] I need my constant involvement with Cochrane in patient care and public health services by providing me social and financial support
Training / guidance	It would be really nice to get involved in a cochrane review where each task you provide a training on so the members of the public and those intrested in systematic reviews join in. My main difficulty has been knowing exactly how the process of evaluating studies generated by the public works and who to contact to follow up. A guide with these simple steps would be a very useful tool for increasing the confidence of those of us who want to learn and participate in Cochrane.
Communication	Cochrane should have some kind to reward to highlight the important work done by PPI community. This may just be helpful for the way I think, but a case scenario or 2 on how someone participated in a task would be great!!! Maybe a case where someone is a beginner, and another case where the person has a little bit of experience. This helps me better imagine what I might encounter. Builds self efficacy. PPI activities can enrich patients' lives. How about writing positive sides of the PPI activities on the website of Cochrane? On the website, it's hard to understand what the PPI is. I believe that the PPI activities provide a sense of purpose in patients' lives. Cochrane should be promoted and disseminated as widely as possible in each country at universities (faculties of medicine, nursing, psychology, pharmacy, etc.; patient, user, and consumer organizations and associations; health administrations; etc.). I think being clear on your purpose to the public would create interest and uplift in engaged public and patients
Other	I like Cochrane, its realistic. I would prefer an easyer searching or helping tools for that. Have a good strategy is important but ensuring its effective implementation is crucial. A strategy that will be context-relevant is easier to implement and needs physical presence. Hence the need for local PPI coordinators at the level of geographical groups. I always ask health professionals I meet if they've heard of Cochrane. Many have not - increasing awareness is also key - 'patient ambassadors'?

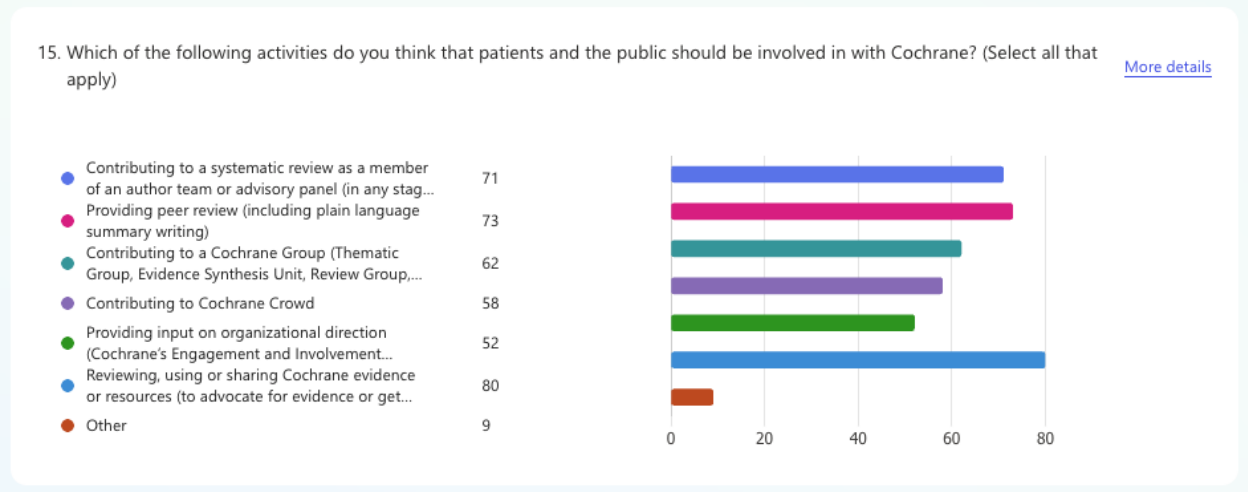
Cochrane author/member of Cochrane group responses:


13. Have you previously/do you currently involve patients and the public in your work with Cochrane?
More details
Yes 54
No 54
50%
50%


14. Which activities have you involved patients and members of the public? (Select all that apply)
More details
For those using Cochrane Engage, please select the specific involvement activities from the list below.
Contributing to a systematic review as a member of an author team or advisory panel (in any stag... 31
Providing peer review (including plain language summary writing) 32
Contributing to a Cochrane Group (Thematic Group, Evidence Synthesis Unit, Review Group,... 25
Contributing to Cochrane Crowd 10
Providing input on organizational direction (Cochrane's Engagement and Involvement... 6
Reviewing, using or sharing Cochrane evidence or resources (to advocate for evidence or get... 25
Other 6
0
10
20
30
40

Other:

- Including Cochrane publications into benefit/risk evaluationsions of treatments at the request of national authorities in DACH region (Germany, Austria, Switzerland, Liechtenstein);
- Guidelines
- Translation
- Asking for evidence considering their specific health problem;
- As HTA person also, involvement of patients&patient organisations during the HTA process;
- Providing talks at Group training sessions;
- We involved the "patients" who are member of our advisory board in Delphi rounds regarding specific projects.


15. Which of the following activities do you think that patients and the public should be involved in with Cochrane? (Select all that apply)
More details
Contributing to a systematic review as a member of an author team or advisory panel (in any stag...
71
Providing peer review (including plain language summary writing)
73
Contributing to a Cochrane Group (Thematic Group, Evidence Synthesis Unit, Review Group,...
62
Contributing to Cochrane Crowd
58
Providing input on organizational direction (Cochrane's Engagement and Involvement...
52
Reviewing, using or sharing Cochrane evidence or resources (to advocate for evidence or get...
80
Other
9
0
20
40
60
80

Other:

- interactions with registered local QPPV functions within Europe and Switzerland;
- Governance and decision-making, e.g. serving on Cochrane advisory panels or editorial boards.
- Contribute to policies on inclusion and engagement.;
- For example, as within HTA process, input on PICO, input for separate Patient sectioon oon their views and experiences on disease area, current treatment options, new health technologies under assessment, any other views important like equity, organisational issues important for medical devices...;
- Being actually involved in Cochrane admin+ research roles;

What barriers currently prevent you from involving patients and the public in your work with Cochrane? Or what barriers are commonly reported by the patients and public that you work with?

Theme	Sample quotes from theme
Time (top 5)	Providing step-by-step guidance to non-professionals requires substantial resources (time and staff) that must be planned for. Time and resource constraints: sometimes involving patients/public requires extra planning, co-ordination and training. Additional time and inflexible timelines
Compensation / financial (top 5)	Lack of funding for compensating people for their time I find it difficult to identify patient associations and to make them understand that their involvement in literature synthesis, such as Cochrane reviews, often has a direct impact on the development of guidelines and, consequently, on clinical practice. In the past, when I tried to involve these associations, even just to share a survey or promote a post from Cochrane Engage, the association asked me to pay a contribution. Lack of funding to pay patients and public at NIHR recommended rates It is not easy to identify people with lived experience who have the necessary skills and can make enough time. [...] For patients to play a significant role funding is needed, which now is rarely available.
Language	Language barriers for non-English speakers.

(top 5)	Language/medical terms
Training / guidance (top 5)	systematic reviews are a tricky topic conceptually so training for patients on the methodology of evidence synthesis would be wonderful Authors may work with non-laypeople language, so it may be difficult to integrate groups o panels Cochrane reviews are too technical and difficult to understand. Acronyms and statistical language can feel intimidating. It is essential to engage patients or members of the general public who have a clear understanding of what Cochrane represents. Prior to involving them in systematic reviews, appropriate preparation is required. Participation cannot be open to just anyone; individuals must receive structured training, potentially through one or several dedicated courses. Moreover, specific competencies or qualifications—reflected in their CVs—should be defined and discussed to ensure meaningful contributions. A model to consider is the NICE methodology, which involves approximately 3,000 trained volunteers (including patients and members of the public) who actively participate in the development of its guidelines. Lack of knowledge regarding the process and importance of involvment(ex: it does not impact their daily life or access to healthcare services) that the research process is unknown and they do not want to get involved in it Level of education Lack of knowledge and guidance how to contribute Lack of training, lower literacy rates I think as someone who contributed to peer reviews, providing a sample for both protocols and systematic reviews, help members to efficiently respond the requirements of the peer review. Technical nature of Cochrane Reviews, Need for more capacity building on the part of patients and Public to enable them effectively contribute to Cochrane
Awareness (top 5) (inc. Awareness of Cochrane Engage)	patients in India are not aware about Cochrane May not see how their input will influence the review. Lack of communication with the network of patients and the public interested in Cochrane's work, especially in Arabic-speaking countries. It is difficult to identify patients / public that actively want to contribute how to find them, how to engage them There should be forum where we can contact patients or public. this will make researcher to contact patients/public. Contacting organisations/groups to recruit patients with the condition that I am investigating The level of awareness among patients and the general public of Cochrane's activities.

Representation	Reliance on existing networks can lead to a lack of diversity. Finding the "right" patient/public with familiarity with evidence synthesis finding the right "representative" Getting "enough" consumers with particular characteristics. There is soo much push to have conusmer invlovement that many consumers are now some what "professional" and the raw voice of someone in the community is getting lost.
Incentives	There are very few incentives for patients or members of the public to participate. While professionals may receive recognition such as authorship, that is rarely meaningful for lay contributors. Finding people who are motivated to contribute and who can align with the research objectives Lack of interest to be involved in tasks requiring effort/time Their unwillingness or fear of participating in scientific research
Communication	Clear communication between academics and lay members Lack of patients' involvement and lack of channels for contact and patients' organisation in such activities Failure of Cochrane to approach people on their lists for assistance with appropriate things. We are busy and don't spend all day on Cochrane Exchange looking for things we could do. Instead, you need to let us know when something relevant to our interests is going through to which we could contribute.
Other	Managing power dynamics between researchers and public/patient members Patients and the public do not easily accept participating in this kind of projects, maybe because they do not really know in advance what is expected from them, and what we need them to do Our group does not have control over Cochrane reviews, only over dissemination, building capacity, and advocacy, so we find that patients and the public are frustrated with gaps in review coverage and sometimes not happy with dissemination and advocacy that is limited to current reviews and has little impact on decisions to undertake new reviews. Difficult for PP to find evidence in the Cochrane Library considering their specific health problem We have consumers as authors on our reviews, but they find the software challenging and we generally send documents for comment/approval as word documents or pdfs. As a review group, we maintained a consumer panel. Many of our contributors preferred communicating directly with people they knew (even if only known virtually) rather than with the wider more impersonal Cochrane Consumer Group Worrying that patients and the public will just be exploited (research is extractive) and not properly supported. Not having access to the Cochrane library Lack of clarity

What kind of support would help you feel confident in involving patients and the public in in evidence synthesis and/or your work with Cochrane?

Theme	Sample quotes from theme
Compensation / financial	Dedicated funding for consumer involvement activities. Accessing funds to help support consumer reimbursement for their contribution
Training / guidance	training for patients and for us on how to involve patients, maybe a shared learning group? Something more informal? A place we can gather an talk openly about the challenges of involving the public in reviews. The important aspect of this would be that it has to be open to all. Not a closed group like the executive or the co-production methods group. And of course it should be free! templates for PPI engagement It would really help to have a clear checklist that defines their role and the time we expect from them. Training for researchers on how to manage power dynamics within teams. This is MORE than "patients should be involved in these steps" -- specific guidance on how to make engagement meaningful and impactful. Perhaps generic resources, but involvement of patients is always going to be contextual to local circumstances. ...Mentorship offers from experienced contributors. ...workshops for researchers on how to engage the public. simple and clear explanations of the processes so that they can get involved, graphic material or videos. Specific guidance for patient involvement. Examples for ways to involve patients and the public meaningfully when review production is not an option would be very helpful. However, I also think that Cochrane needs a new model for how to prioritize and support reviews that are of interest to patients and the pubic. Working on awareness and training sessions leading to their active commitment (e.g., risk of bias assessment) Learning tool about how to participate in evidence synthesis in different languages; exchange between Cochrane Groups how to involve PP in Group activities Guidance, advice, mentoring and input from experts making materials that make it easier for the public to understand what Cochrane involvement means and what commitments are going to be involved
Awareness	Awareness about the work of Cochrane and why it is important. Access to patient networks or registries

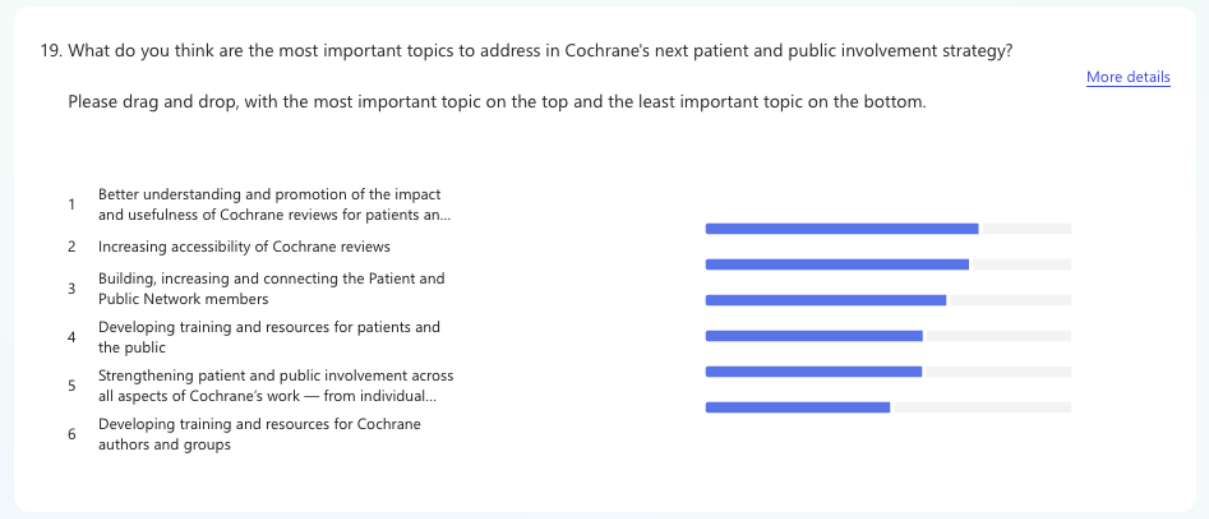
(inc. Awareness of Cochrane Engage)	I think the issue is that many healthcare professionals do not integrate research activities into their daily practice. As a result, the number of patients who are genuinely interested in evidence synthesis is smaller than the number of those who care about research in general. Perhaps the solution could be to reach out to community-based physicians, since they are the first point of contact and key communicators of scientific information. having a centralized structure (like a dashboard for example, or a go-to person) could help; like - if we know how to reach the right people Building local associations / patient organisations from within communities that can be a bridge between patients and Cochrane affiliated centers dashboard; database with consumers based on a topic, skills
Leadership	Cochrane leadership endorsement that consumer involvement is a priority. Also, it would be helpful if this was a section added in the reporting guidelines, forcing reviewers to involve patients. Firm, clear and rational plan of involvement of patients, and readiness/reality of work along it
Representation	A patients/ public involvement network with representatives from many countries/languages
Other	Working with PPI experts, either fellow academics or PPI co-authors Having permanent advisory groups that we can consult—free from conflicts of interest. Having someone there to help them at a moments notice with questions. If it is difficult, they may not continue. To have an structure plan to involve patients and public. Probably to perform a pilot once a group of patients /public has been selected. It also quite important to have wide representation of all continents. Cultural and social context is very important A daily, live Cochrane access system to information and question/answer could be helpful

How do you think we can make Cochrane reviews more accessible and understandable to patients and the public?

Communication Overwhelming response in this theme – helpful/innovative quotes included here	...visual aids and clear key-message sections would improve understanding. Many patients struggle with technical terminology, so offering clear explanations, short videos, and patient-friendly summaries would greatly improve understanding. Try to make short them down, make reviews and plain language summaries available through social media, or directly to different patients' organisations. ...collaboration (systematic) with local media to attract the patients (public) to look at them.

	For standard reviews, perhaps have infographics/summary of the review in plain English. The document can have a link to the original review if they would like to read more about it In a standardised way, a more figurative based plain language summary ie less text. Overhaul format. Deploy communication strategies specifically targeting patients and the general public: press releases for the general public, consumer associations, etc. Plain language summaries should be written better. Storytelling is helpful to receive people's interest ...Collaboration with graphic designers and video makers may be helpful ...working with realiable and trustworty influencers We should relying more in shareable graphic formats, like infographics, visual abstract, bullet points. ...translating technical content into information that is easy to understand, incorporating humorous examples and integrating the cultural and social contexts of different countries. Additionally, it is important to identify methods to quantify the reach and impact of these communication channels and to evaluate their effectiveness. We should create more advertisement on social media and have to increase awareness session videos on youtube. Clearly state what the evidence means for everyday decisions. Include outcomes that consumers care about. Short podcast to explain the review's findings. Include FAQs and what does this mean to me sections.
Collaboration	... Involving patients in the final editing process is also important to ensure the content is truly relevant and meaningful. move away from the current model of plain english summaries - we need to be more creative with our knowledge translation and sharing, INVOLVE patients in the reviews, through the reviews, prioritise reviews that are of importance to patients, simply ask people what evidence they want and build a team who will produce that research WITH the public. More research led by the public, for the public - like The People's Review initiative. By supporting groups (and authors) in how to develop PPI; involving P&P; providing packaging in accessible languages, formats, etc... Empowering and training people with lived experience. Involve patients and the public from the start and crucially in the design of a dissemination strategy (to include communication re. the review throughout its conduct and not just at the end). Collaborate with Wikipedia, be more visible on SoMe, organize dedicated events, collaborate with hospitals/info boards
Language	Translations, culturally relevant examples and shorter, layered formats could further enhance accessibility for patients and the public. Make Plain Language Summaries, especially translated PLS, easier to find

	Free availability in multiple languages
Training / guidance	...training and capacity building for patients and public
Other	Offer an increased schedule of a live question/answer timetable system in multiple languages. Create applications with easy access to evidence. Giving free access to the Cochrane library Public friendly database to look up health topics. Plain language summaries should be the first thing they see, with links to the scientific evidence if desired. Making them open access from it first publication, with no embargo period The reviews can be published in small health care centers. Publishing reviews including their impact on communities on the short and long term. Involving students early through school projects (increase early awareness about Cochrane work and community involvement)


19. What do you think are the most important topics to address in Cochrane's next patient and public involvement strategy?
More details
Please drag and drop, with the most important topic on the top and the least important topic on the bottom.
1 Better understanding and promotion of the impact and usefulness of Cochrane reviews for patients an...
2 Increasing accessibility of Cochrane reviews
3 Building, increasing and connecting the Patient and Public Network members
4 Developing training and resources for patients and the public
5 Strengthening patient and public involvement across all aspects of Cochrane's work — from individual...
6 Developing training and resources for Cochrane authors and groups

Do you have any further comments you would like to share based on your responses?

Compensation / funding	I think the only way to move forward with involving more people in reviews across Cochrane is by providing fair compensation to the PPI contributors AND by sourcing sustainable funding for co-production. Is there a route for funding with the ESIC Welcome Trust funding?
Awareness	There should be more levels of involvement available for patients and public. For example, thinking of the Ladder of Citizen Participation (Arnstein, 1996), not everyone want to be involved in a deeper level (like writing a review) at first. That kind of committment can be discouraging. Starting with less responsabilities and then move up in the ladder should be available to citizens. I have a strong feeling that there is a lack of knowledge towards EBP and Cochrane among the clinical community of SLPs in Italy. I think we as Cochrane should address this gap.

	When I ask people around me (including health professionals), Cochrane is virtually unknown. However, I have noticed that SRs are perhaps more often mentioned in newsletters.
Leadership	Patient input/involvement should be mandatory for Cochrane Reviews
Other	Most initiatives are from the Global North. Future initiatives should be 50/50. Consider working closely with the Co-production working group and the MuSE Consortium The goals and strategies should be driven by community needs, and personalised to each community . Over the years, we have found that a personal touch works best. At least at the start, a personal email/communication from an individual rather than a generic welcome might work best (although this would require resourcing). I've been logged as a consumer for years, and have not been utilsed for a long time. [...] Be more proactive in approaching suitable consumers, rather than waiting for them to self select.

Member of evidence community

Organization affiliation representation

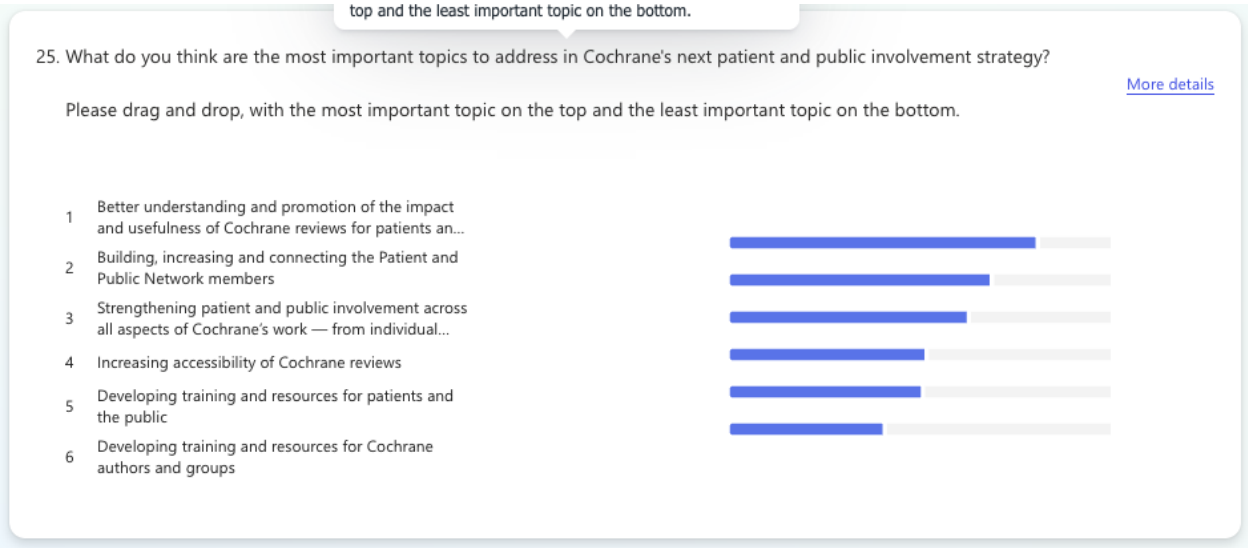
General categorization provided for anonymity:

- Non-profits
- Funders
- Government
- Universities
- Private organizations
- Freelancers and consultants

What barriers currently prevent you from involving patients and the public in your work? Or what barriers are commonly reported by the patients and public that you work with?

Time	Project timelines and funder priorities
Compensation / financial	Lack of funding for paying patients and members of the public for their work. Cochrane is an example of this bad habit of treating all kinds of work as volunteering, unpaid work. PPI work involves high responsibility for decisions, and valuable experiences and insights. You pay for research workers experiences, expertise, and work. Why not pay for members of the public as well? Cost and time. Cost in terms of need additional paid hours in many, if not all, of the steps of a systematic review to genuinely involve patients and the public.
Language	Communication and scientific language

	... Another significant barrier is the lack of a common language between healthcare professionals and patients, which often leads to misunderstandings.
Other	Lack of interest for guideline production, insecurity because of lack of basic knowledge How to engage Cochrane reviews to healthy patients or make patients that are completely outside the healthcare fields interested in learning about Cochrane PPI members feel researchers are not transparent, flexible and inclusive. As part of my work our group tries to meet this criteria and aims to close feedback loops so members can track their direct involvement on projects and know what is next. Misinformation that are circulating among public and affect patient are the most common barrier Resources


top and the least important topic on the bottom.
25. What do you think are the most important topics to address in Cochrane's next patient and public involvement strategy?
More details
Please drag and drop, with the most important topic on the top and the least important topic on the bottom.
1 Better understanding and promotion of the impact and usefulness of Cochrane reviews for patients an...
2 Building, increasing and connecting the Patient and Public Network members
3 Strengthening patient and public involvement across all aspects of Cochrane's work — from individual...
4 Increasing accessibility of Cochrane reviews
5 Developing training and resources for patients and the public
6 Developing training and resources for Cochrane authors and groups

Do you have any further comments you would like to share based on your responses?

- Despite increased awareness and emphasis on the value of PPI partners, I think some of the barriers for participation remain longstanding; however, understanding role is also multi-directional, and the value of trained, early career researchers on the ground working in partnership is important - not only senior academic leaders publishing about the value of PPI

Combined responses:

What country do you currently live in?

Below is a summary of respondent countries. Total from each country is not included for anonymity. Total countries = 62

- Argentina
- Australia
- Austria
- Finland
- France
- Gambia
- Kenya
- Lebanon
- Malaysia
- Saudi Arabia
- Serbia
- Spain

- Belgium
- Brazil
- Cameroon
- Canada
- Chile
- China
- Colombia
- Croatia
- Denmark
- Ecuador
- Egypt
- Ethiopia
- Germany
- Greece
- Guatemala
- Hong Kong
- Hungary
- India
- Indonesia
- Iran
- Ireland
- Italy
- Israel
- Japan
- Mexico
- Morocco
- Netherlands
- Norway
- North Macedonia
- Nigeria
- Pakistan
- Peru
- Poland
- Portugal
- Russia
- South Africa
- Switzerland
- Syria
- Tanzania
- Tunisia
- Uzbekistan
- United Arab Emirates
- United Kingdom
- United States of America
- Vietnam

Other community, organizational or patient advocacy groups similar to Cochrane, engaged with:

- Patient advocacy organizations
- PPI work
- Research
- Non profits
- Funders
- Government

What values do you think should guide our Patient and Public Involvement Network in the next strategy?

AI support for grouping and listing top 10, from most often to least often mentioned:

Rank	Theme	Mentions	% of statements
1	**Inclusivity & Representation** (inclusion, diverse voices, representativeness, "everyone is heard")	47	23.3%
2	**Transparency & Openness** (transparency, openness, conflicts of interest)	44	21.8%
3	**Accessibility, Clarity & Usability** (access, plain/clear language, usable/approachable)	33	16.3%
4	**Equity, Fairness & Justice** (equity, equality, fairness, justice)	30	14.9%
5	**Impact, Relevance & Value** (adding value, relevance, usefulness, real-world impact)	29	14.4%
6	**Collaboration, Partnership & Teamwork** (equal partnership, co-creation, teamwork)	27	13.4%
7	**Respect & Dignity** (mutual respect, dignity)	23	11.4%

8	**Communication, Listening, Engagement & Dissemination** (listening, communication, engagement, dissemination)	21	10.4%
9 (tie)	**Ethics, Integrity & Honesty** (ethical practice, integrity, honesty, bioethics)	19	9.4%
9 (tie)	**Trust & Trustworthiness** (trust, trustworthy information, building trust)	19	9.4%